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ABSTRACT

The articles in this booklet were developed as part of the Infant/Parent Education Project, operated by the Pediatric Department of the Charles R. Drew Postgraduate Medical School (Los Angeles, CA) and funded by the Bureau for the Education of the Handicapped. Under the project, a model program was developed to serve handicapped minority infants (birth to 18 months) and their families. This program focused on the need to communicate in the language of the inner city minority groups served and addressed social and cultural factors unique to these populations. Articles in the booklet include: (1) "A Social Hygiene Approach to the New Morbidity," by Robert J. Schlegel; (2) "Early Intervention: Does It Make a Difference?" by Carol Phillips; (3) "The Antecedents of Handicapping Conditions," by Xylina Bean; (4) "Human Service Delivery for High Risk Infants," by Barbara B. Richardson; (5) "Cultural Pluralism in the Delivery of Services to High Risk Minority Children," by J. Michael Ortiz; (6) "Developmental Activities for Infants Using the Family Environment," by Irene Herndon; and (7) "An Ecological Model for Intervention with Inner-City Poor and/or Minority Hanicapped Infants and Their Families: The Community," by Vivian Weinstein. (WAM)

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An Ecological Model of Services to Inner City Minority Handicapped Infants

A program in the

Charles R. Drew Postgraduate Medical School
Pediatrics Department
Child Development Division

UD 022 641

Papers
from the Experiences of the
Infant·Parent Project

An Ecological Model of Services to
Inner City Minority Handicapped Infants

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Introduction

The Infant/Parent Education Project operated by the Pediatric Department of the Charles R. Drew Postgraduate Medical School was funded by the Bureau for the Education of the Handicapped (BEH), HEW in July of 1977 to develop a model program serving handicapped minority infants. The project was designed to serve infants, birth to 18 months, referred primarily from the Intensive Care Nursery at Martin Luther King Jr. Hospital. The initial program design was based upon a traditional service model. Although the Pediatric Department was keenly aware of the special conditions that prevailed in the community served by the King/Drew Medical Center located in an inner city poor minority community, this knowledge was not translated into the service design.

Early in the process of developing and implementing the services to the children and their families it became clear that unless the staff placed the unique needs of the population to be served, as reflected in the ecology of the community, as central to its service model, the program would be of limited use. The staff became increasingly aware of the need to communicate in the language of the population served, culturally different values, child rearing practices, perceptions of and behavioral responses to the handicapped and the impact of poverty and all its attending problems, as well as the lack of responsiveness of the service institutions. As a result, new and different methods responsive to the families served began to be explored, developed and implemented.

The articles in this booklet are a reflection of this developmental process, living, changing, and evolving service delivery model which was successful and that we came to call An Ecological Model of Services to Inner City Minority Handicapped Infants. The papers included in this publication were delivered at different times during the first three years of the project. The project has continued with current funding from the South Central Regional Center, Development Disabilities. The ecological model continues to develop and change as the staff continues to serve children and families. We feel the material eminating from the project can be useful to others in similar communities if it is seen as needing constant change and modification as appropriate.

We dedicate this publication with deep appreciation first to the infants and their families who were very patient with us, and to all the staff members of the project and staff of the Intensive Care Unit, Martin Luther King Hospital, who contributed their energy and skills: Barbara Richards, Ph.D., Gretchen Fothergill, Regina Hicks, Gertude Ortiz, Elizabeth Najera, Linda Jenkins, Torcy Wiley, Ed. D., Betty Pallansch, Irene Herndon, Kerry English, M.D., Xylina Bean, M.D., Berta Johnson, MSW, Carolyn Wright.

Vivian Weinstein
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A Social Hygiene Approach to The New Morbidity

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and
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Recently much attention is being paid to a phenomenon known in the medical world as "the new morbidity" (1,2). This consists of a group of socially engendred diseases and disabilities, including those due to such problems as drug abuse,venereal disease, teenage pregnancy, child abuse and violent crimes such as homicide. For the most part these problems affect children, or trace their origins to the childhood years.

Opinions vary within the medical world as to whether these conditions can be considered medical or not, and also whether or not they are a legitimate concern of the medical profession. Certainly the problems themselves have proven remarkably resistant to heavily subsidized medical efforts, as evidenced by their constantly increasing prevalence. While they affect all segments of the American population, the new morbidity plagues poor, urban and minority people most particularly (3).

Consequently, when a new academic Department of Pediatrics was founded in the Watts area of Los Angeles in 1971, its first order of business was to consider this set of problems. In this essay I will describe briefly the basis for our decision that the new morbidity indeed requires medical participation, but that it will not yield to traditional medical approaches, requiring instead a social hygiene methodology.

The Over-Narrow Agenda

Those physicians who seek freedom from involvement in the prevention and cure of the new morbidity neglect both the social responsibilities of our profession and the economics of the health care fields. Individuals affected by the new morbidity do seek services from physicians, clinics and hospitals. What they receive is hurried curative care for the immediate crisis, often with no attention paid to their fundamental illness or to its prevention. Hence, physicians and health care centers are already involved whether they choose to be or not. The real question is how to be effectively involved.

With regard to social responsibilities of the profession, medicine continues to enjoy the highest regard among American occupations (4). Communities lacking a physician express great insecurity and demand redress of their perceived need from elected public officials. Our federal, state and local governments are all heavily involved in financing medical care. These include paying for a large part of the medical education of physicians during both graduate and postgraduate years. This perceived social need and professional prestige, merited or not, accounts for the virtually unlimited opportunities granted to the properly prepared physician for community leadership and for improvement of local child care, education and welfare institutions.

Yet, in recent years, more and more physicians, hospitals and clinics have been moving away from the nation's largest centers of unemployment and hopelessness (5): root causes of the new morbidity. Physicians, health care institutions and health policy experts neglect to a degree the enormous impact which the closing of a hospital or clinic can have on a local community. This is especially true of full service institutions providing academic training for physicians or for other health care workers in the more than 400 health care fields. These fields currently provide over 6,000,000 jobs: more than the automobile and utility industries combined. They motivate, inspire and train the young for stable, career oriented, professional lives. By depriving our neediest communities of these powerful economic complexes, the medical profession has become one cause of the new morbidity.

Categorical Programs

The medical model of diagnosis and treatment for clearly defined problems is an approach not

limited in its application to curative medicine. Public health approaches, also, tend to deal with individual problems such as drug abuse or tuberculosis, without regard to the underlying factors — malnutrition, lifestyle, or personal attitudes that make a child vulnerable to disease. This "categorical approach" is expensive. At the local level this approach produces special interest bureaucracies which render inferior care by part-time physicians in public health departments (6). It would prove far less expensive to provide full services on a longitudinal basis by a single agency capable of dealing with all of the separate categorical problems. If that agency were equipped to deal with the elemental causes common to those problems through health promotion, it would be more effective than current programs limited to systematic care.

Unfortunately, the education and social service fields have also adopted similar categorical approaches. In addition, their programs overlap with those of the health care fields. It would prove far less expensive to deal with the child as a child, rather than as part-time pupil, patient or client. Of course, if poor education leads to high maternal and infant death rates, physicians have a legitimate concern with education. When children cannot learn because of a handicapping pulmonary or neurological condition, teachers need to know about health and medical care. However, these needs can be met by tightly coordinated service centers involving all of our professions at the local level.

None of these categorical approaches is truly etiological. Tuberculosis will always be with us if we confine our attention to health screening tests, the treatment of individuals and the screening of immediate contacts. We must also deal with the poor nutrition and over-crowded housing that continuously spawn new cases. The diagnosis and treatment of lead encephalopathy in communities where it occurs should not be disconnected from efforts to remove hazardous lead painted surfaces. Sex education courses are not likely to prove useful unless they deal with the limited occupational expectations of young people who lack the motivation to defer sexual activity and pregnancy.

To illustrate, dog bites are seen frequently in our pediatric clinic. They sometimes result in lifetime scars of the face. Also, although no rabies has occurred in the child population of our region for many years, it is necessary to treat some patients with a long, painful and even dangerous course of antirabies vaccine when the dogs cannot be identified for veterinary observation. In some instances parents and teachers have failed to see to it that children are seen by physicians following deep dog bite puncture wounds. The prevalence of dangerous dog bites is accounted for by the practice of keeping watch dogs in our high crime area. Many of those animals are unlicensed, and unimmunized.

Rather than limiting our medical treatment to emergency care of the wound, it seems to us that we have a responsibility to attack each of these more basic causes of childhood injury and its complications. Thus, parents and teachers should be informed about the necessary first aid and medical care of dog bites. Prevention programs involve cooperation with animal control agencies and moral suasion concerning animal ownership responsibility in local community organizations. Finally, programs of health promotion eventually do involve concern about the underlying problem of crime — particularly juvenile crime — the main problem of our community. We have programs to offer alternatives for the child who is drifting toward that underworld existence that makes life so unsecure in our community — a thing of barred windows, watchdogs, and perpetual vigilence.

In these programs two characteristics have seemed most important to us for health promotion (1) inculcating in the developing child a sense of worth (2) providing the child with opportunities to acquire the habits of disciplined learning required for success in our technical society. These are the real antidotes to juvenile crime prevention.

A Social Approach

Proceeding from this analysis we have taken a new tack in eliminating the great killers among our child population in Watts. In our system, physicians working in concert with others, such as parents, teachers and social workers seek to address directly those needs of children that, in their unfullfillment, lead to the major morbidity. This calls for engendering motivation as well as providing education to children of all ages for the purpose of helping them to lead healthy and secure lives. It requires assistance to parents in improving the quality of their lives and their opportunities for parenting. A system of child care centers, public school programs, recreation facilities and vocational planning programs has been developed, tying together parents, teachers, physicians and social workers in joint activities.

A medical department pursuing this course has several distinct advantages. First, it has a natural

service population in the form of patients seeking both curative services and also health maintenance care for pregnancies, newborn management and health supervision of the older child. Second, it can gain the cooperation of local child care centers, schools, adoption agencies, foster care homes and other centers of community life by offering to them scarce pediatric services. Also, it is possible to educate medical students, resident physicians and others in the social hygiene aspects of urban pediatrics. Through selection and instruction of students, the center sees to it that many remain in underserved communities for the practice of medicine and that they know how to be most effective when they do so. It then becomes possible to amplify medical leadership and community development by interfacing with an informed, private practice sector in medicine and in other health related fields.

This social hygiene approach is also rooted deeply in the concept that parents rear children—the providers of children's services do not. It is necessary to engender in the community a group of well informed parents who will provide constructive leadership for child guidance and child rearing. This can be accomplished through well defined, competency based instruction in the parent participation activities conducted in our child development service programs.

Also involved is the construction of community action groups from children's service agencies. These groups, by working together, create the necessary linkages between child-centered community services involving health, education and welfare. They also act as the necessary change agents in educating physicians, teachers and social workers of the future with the special skills, knowledge, and attitudes required for interdisciplinary approaches to children's services. Health workers play a necessary role not only as the providers of technical services, but as the teachers of health and science, as the developers among children of career motivation and guidance as well as a source of inspiration to children through role modeling. They can be enterprising agents for economic development of the community.

These community based child development services in no way interfere with the establishment or maintenance of high standards in the provision of curative services or in the quality of education to carry out such services. Rather, they add an exciting new dimension in professional service and education, challenging us to creative thought and research. While it is true that every faculty member at King/Drew is expected to carry the responsibility for at least one organized extramural program, these activities may include either bioscience or psychosocial research. Thus, useful traditional standards for individual faculty performance can be maintained with little modification.

There are many basic strengths in communities like Watts. Despite their media-fostered reputation of violence, disorganization and hopelessness, many inner city dwellers are property owners, have occupations as nurses, social workers, school teachers, ministers, skilled tradespersons and the like. These strengths should be related to when building social and economic institutions necessary for good health among children. This productive subpopulation provides guidance, volunteer services, public relations aid and is a source of joint project development for program managers in basic areas such as housing, recreation, counseling and citizen information.

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The Antecedents of Handicapping Conditions

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The antecedents of handicapping conditions in the infant are multiple. Advance in obstetrical and neonatal care in this country in the last few years has resulted in a marked decrease in the death rate from factors previously associated with high fetal loss, and as might be expected, there has been an accompanying increase in infants surviving with significant physical and/or neurologic handicaps.

Factors which result in infants at risk for increased mortality and morbidity can be divided into those risks present *preconceptually*, those occurring during *pregnancy*, those presenting during labor and those developing *after delivery* during the neonatal period.

It has been well documented in multiple studies that the highest infant mortality and morbidity is found among women who are poor and non-white. The specific components of poverty which appear to increase the incident of high-risk pregnancies include *poor housing, poor nutrition, lower educational level, increased incidence of inadequately treated pre-existing medical problems such as hypertension and anemia* and an *increased incidence of inadequate prenatal care*. The presence of these risk factors results in a three- to four-fold increase in the chance of having an infant who is low-birth weight and/or premature. These are the infants who have the highest risk of subsequent mortality and morbidity.

The other preconceptual risk factor I will discuss is maternal age. Maternal age of less than 16 years or greater than 35 years is associated with a high risk for infants with congenital abnormalities and developmental delays. The highest overall incidence of infants with developmental delays and congenital abnormalities is found among surviving infants of older mothers. This is primarily due to the increased incidence of chromosomal abnormalities in these infants. The incidence of chromosomal abnormalities in the infants of mothers over 35 years of age is two percent compared to 0.15 percent in the overall population of infants. The highest risk is in the women between 40 and 44 years of age, where, for example, the incidence of Down's Syndrome increases to one in 40.

Though Down's Syndrome is the most common chromosomal abnormality associated with late maternal age, other chromosomal abnormalities such as trisomy 13, trisomy 18, and Klinefelters Syndrome are also increased. In addition, the older woman having her first child has a greater incidence of having an infant who suffers a traumatic intracranial hemorrhage. This apparently is related to the diminished elasticity of the pelvic outlet which results in an increased incidence of difficult traumatic deliveries, increased fetal distress prior to delivery, and increased need for emergency cesarean sections. All these factors may result in a brain damaged infant.

Despite a general decline in total births to all teenagers nationally, the proportions of teenage births increased from 17 percent of all births in 1966 to 19 percent in 1975. The birth rate to older teenagers, 18 to 19 years, dropped substantially, whereas the birth rate for those 15 to 17 years of age increased by 22 percent, and the rate for those under 15 years of age increased by as much as 42 percent.

As compared to women 20 to 24 years of age, the teenager has a greatly increased risk of anemia, abnormal bleeding, toxemia, difficult labor, cephalopelvic disproportion, and maternal death. As might be expected, this results in higher infant mortality and morbidity. The frequency of low-birth weight infants born to all adolescents as compared to females 20 to 24 years of age is 30 percent higher, and for adolescents under 15 years of age,

the prematurity rate is two times that for females 20 to 24 years of age.

A recent collaborative National Institute of Health perinatal study found that babies born to mothers younger than 15 are two to four times more likely to be neurologically abnormal than babies born to women 20 to 24 years of age. Unlike women who have their first child in their twenties, teenage mothers increase the risk of both perinatal mortality and prematurity by each additional birth occurring before the age of 20, a full 6 percent of all first babies, and almost 10 percent of second babies born to girls under 15 die in their first year.

The risk of developing a congenital intrauterine infection is greater among women of lower socioeconomic groups. Cytomegalovirus, Rubella and syphilis are the most common intrauterine infections seen in these groups. All the intrauterine infections are characterized by the production of infants with severe neurological damage and multiple congenital anomalies.

Smoking has been well documented to cause intrauterine growth retardation and so called small for date infants. Excessive alcohol ingestion during pregnancy can result in infants with severe neurologic deficits and multiple congenital abnormalities — the so called fetal alcohol syndrome. Newer data, however, indicates that even moderate alcohol ingestion may result in infants with neurologic damage, but of a less severe nature. Drug abuse — heroin, barbiturates, and PCP, for example — result in infants who are small for date, tend to be depressed at birth, often go through drug withdrawal, and have a higher risk for later developmental problems.

There are a number of problems which occur during labor which may contribute to subsequent morbidity in infants. These include abnormal presentations, such as breech delivery. As shown in the chart, abnormal presentations have an increased risk of prematurity, congenital malformations, and fetal asphyxia. Increased delivery of infants by cesarean section has actually decreased the incidence of sequelae in these infants. Other problems such as placental accidents, eclampsia, preeclampsia, precipitous delivery, and uterine rupture all may lead to increased incidence of fetal asphyxia and subsequent brain damage in the infant.

Finally, I would like to spend a short time talking about neonatal risk factors. As previously mentioned, the incidence of low-birth weight and premature infants is increased in any area where there is a concentration of non-white, lower socioeconomic families. The result is that the Southeast Region has one of the highest prematurity rates in Los Angeles County.

The low-birth weight infant not born premature, so called for gestational age infant, has an increased incidence of having acquired an intrauterine infection (such as CMV, rubella, or syphilis, as previously discussed) increased chance of being born with congenital abnormalities, does not tolerate labor and delivery well, and consequently has an increased incidence of neonatal asphyxia and brain damage at delivery. Improvements in postnatal care are probably largely responsible for the striking decrease in the incidence of moderate and severe mental and neurologic handicaps in these infants. However, studies seem to suggest that later status of SGA infants is particularly dependent on postnatal environment. A stimulating postnatal environment and optimal nutrition in the preschool years is a requirement for all children, but perhaps particularly for those who were undergrown in utero.

The prognosis for the low-birth weight infant born prematurely, though markedly improved in the last few years, is still poor. These infants have increased incidence of respiratory disease, metabolic problems, such as hyperbilirubinemia and hypoglycemia, increased incidence of infection and of intracranial hemorrhages. As a result, they form a group with a substantial incidence of subsequent neurologic deficits at discharge.

In summary, the preceding discussion indicates that the potential morbidity in infancy is substantial. In 1972, when this hospital opened, the Southeast Health Region had the highest infant mortality rate in Los Angeles County. Recent figures show a marked decrease in this, but we still have the highest infant death rate in the county; and further, the death rate in the first year of life has increased. This increase probably reflects the fetal and neonatal death rates, and further indicates the significant morbidity present in the infant population during this first year.

Early Intervention: Does It Make A Difference?

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The notion of "interventior" stems from developmental research which suggests that there are many things about the human organism that can be shaped in the early years of life in ways which enhance or deter development in the later years. Medical science, for example, has long known about the plasticity of the central nervous system during infancy and the early years and the beneficial efforts of early stimulation on developing animals and humans.

As a result, medical, social service, and educational settings have developed programs to systematize and structure practical experiences for high-risk populations of infants and young children which basically have as their goal the prevention and/or amelioration of developmental disabilities. The approaches have been many and varied, as have been the outcomes and evaluation results. Some studies report that intervention does make a difference, others report that it does not. But a simple yes or no answer to our question leaves us without any real information which can serve to guide future intervention efforts within any community. What is needed is specific information about two things: 1) What differences in the lives of children do intervention strategies make? 2) What distinguishes the programs that make a difference from those that don't?

Concerning the first question, the most well documented efforts at evaluating early intervention programs have been those assessments of programs aimed at combatting the destructive effects of poverty through educational intervention.

Bronfenbrenner (1974) has reviewed studies of educational intervention programs, basically Head Start studies, conducted during the 1960's. These studies checked on children two to four years of age after leaving the programs; both home-based and center-based. They measured information in the cognitive area only; i.e., I.Q. test score on Stanford Binet, and measure of academic achievement on standardized tests. It is important to note that in most studies there were no measures of the child's sense of fulfillment as a person—indices of self-esteem, emotional security, etc.,—nor were there any measures of social skills, such as generosity, cooperation, responsibility, etc., developmental behaviors which the programs were aimed at, as well as cognitive growth.

In any case, on the whole, the results of the studies were basically that cognitive gains made were soon lost. This pattern was most strongly evident in the center-based programs where children were instructed in "schools":

1. The programs produced substantial I.Q. gains which were maintained as long as the program lasted.
2. The groups of children did not continue I.Q. gains after one year of intervention and after the initial increase, the gains wash out. One year after termination from the program, the I.Q. starts to drop, and by four years later, it drops back to its original level.

Results from home-based studies where children were instructed at home were generally the same, but with slight variation:

1. The programs produced substantial I.Q. gains which continued to improve as long as the program lasted.
2. The I.Q. gains demonstrated during the program held up three to four years after intervention was discontinued. There is some erosion, but it is smaller than those of children in center-based programs.

Bronfenbrenner speculates that the differences between the two types of programs may not account for the differing effects so much as the nature of the difference between the subject groups in the two types of projects. Parents in home-based programs may demonstrate more "motivation" by virtue of the fact that they volunteered on the basis of their willingness to participate in the activities with the child, and their willingness to "let a stranger into the house."

Even though these studies generally pointed to the lack of long-lasting effectiveness of the intervention efforts, both from home-based and center-based programs, it is important to note that

the one program which indicated the most long-lasting and positive results distinguished itself from the other programs in two specific ways: ways which help us to address our second question (What distinguishes programs that do make a difference from those programs that don't?). Phyllis Levenstein's home-based program in Mineola, New York, had two special aspects:

1. The target of the intervention was the mother-child dyad as an interactive system, not the individual child.
2. The agent of intervention was not the teacher, but the mother.

As a result, the intervention was not restricted to the period when the tutor was in the home, nor to the length of the program, but continued as long as the patterns of joint activity between the mother and child endured. These conclusions reinforce basic principles of development in the early years which stress the notion that "the psychological development of the child is enhanced through his involvement in progressively more complex, enduring patterns of reciprocal contingent interaction with persons with whom he has established a mutual and enduring emotional attachment" (Bronfenbrenner, p. 26). This is a point to which we will later return.

These studies were disappointment to many practitioners and community people like myself whose experiences in these same programs had led us to believe just the opposite. The researchers were saying that these programs had failed, but we knew better. We knew about the health gains, the social gains, the emotional gains, and the educational gains; we knew about all the other things that demonstrated to us that the experiences these children have in Head Start programs are beneficial, and in fact, offset some of the negative developmental trends that poverty children are expected to demonstrate. But we didn't have a study to say so. At least not until 1977. A group of researchers at Cornell University (Darlington, Richard, Royce, Snipper, Murray, and Lazar) wanted to respond to the notion that preschool did not have a lasting effect on children's intellectual development by again investigating the effectiveness of these programs in improving later school competence. They thought, however, that it was due time for an examination of these effects well beyond the primary grades.

So, what they did was identified 11 research studies done in the 1960's on three and four year olds in intervention programs, each with a matched sample of children not in programs. These studies were spread out all over the country in the northeast, southeast, and midwest, and had included 2,700 subjects, 94 of whom were low-income Black children. Of these original subjects, the Cornell team found 74 percent of the subjects (1,600 children) who were by then between the ages of nine and 19 years with the median subject in the seventh grade.

Five types of data were collected: School record information; standardized achievement test scores; Weschler I.Q., interviews with subjects; and interviews with parents. The results: I.Q. findings replicated earlier studies: no effects after three to four years after intervention.

However, since they were interested in "more direct measures of school success," they gathered information from the school records and (1) whether the child had been retained (held back) in any grade in school; and (2) whether the child had been assigned to special education classes at any time during their school career. Special education was defined as trainable mentally retarded, educable M.R., learning disabled or emotional disturbance, NOT speech and hearing difficulties. Although there were varying policies across the country concerning retention and assignment to special education, it was felt by the investigators that both indicators represent the fact that the child had not met the school's standard for normal progression. So using those two measures, what did they find? That the children who had attended preschool were more likely to meet the requirements of their schools than children with no preschool experience. For each measure separately, intervention seemed to have a stronger effect on rate of assignment to special education than it had on grade retention. The median rate of assignment to special education for control was 29 percent and for treatment children 14 percent; for retention the median rate was 37 percent for controls and 25 percent for treatment.

While the evidence is still not all in, these recent indications point to the conclusion that intervention in the early years, at least with a low income population, may have the long-term effects of bettering one's chances for success in school.

What about intervention with infants and children who are at risk because of developmental disabilities? Much less is known about the effects of intervention with these children, partly because systematic study of well designed studies has a recent history. Much of the preliminary evidence, in fact, comes from small isolated studies of children and speculation from animal studies.

According to Tjossem (1976), infant stimulation in the form of handling or other sensory stimulation is the most prominent intervening variable in studies of infants. The Scarr-Salapatek and Williams (1973) study demonstrated developmental gains as measured by the Cattell scales for biologically impaired low birth weight babies who were given extra handling and exposure to human faces and voices, as well as patterned visual stimulation in the hospital nursery, and then given weekly home visits from a social worker who provided instruction and demonstration to the mothers in developmental stimulation. Other projects of intervention with premature babies involving frequent handling and sensory stimulation in the first few weeks of life reported favorable gains in early development—more responsive babies, and similarly, more responsive mothers. Long range effects are not yet known.

The principles of operant conditioning (or behavior modification) have, often in clinical settings, also been successfully employed by parents and teachers in aiding biologically impaired children to master specific tasks. Gross motor, fine motor, language, perceptual-cognitive and personal social training have been demonstrated to be positively affected by a variety of programs in which trained professional personnel work directly with the child and/or teach the parent techniques for working with the child.

Sensorimotor patterning as a treatment method for children with brain damage emerged in the 1960's. Testing the effects of this method have only begun recently (175, Neman, et al. in Tjossem, page 23) and results are as yet undetermined. Efforts such as these seem to characterize the current thrust in services to developmentally at risk infants and young children whether in hospitals, pediatric outpatient care, early schooling or developmental day care. Their focus is to provide direct care and education for the child. ***A focus, which has been argued, is not enough to facilitate optimal development in the long run.***

According to Ethel Kass (1974), approaches directed at changing only the behavior of the child over a short period of time may have limited consequences since the basic environment is unaltered. More long-lasting effects are obtained with approaches which continue to generate reinforcing environmental events, which strengthen maternal sensitivity and skills, and which create a mother-child interaction in which the mother experiences success and the infant progresses to his/her maximum capacity.

Supportive of this approach are many writers including Shaefer (1976) who advocates moving the focus of intervention reasearch away from the study of monads and dyads to the study of tryads and ecosystems—towards looking at family networks, and parents/professionals/child networks, towards strengthening and supporting the child's interactions in his/her famiiy and community environment.

Bronfenbrenner (1974) speaks to this notion of the need to address the "ecology of early intervention." He argues that any situation which does not permit parental functions to occur, child development is impaired. In his discussion of the context of deprivation, he asks, "what makes it difficult for parents to meet the basic psychological needs of their children?" How can we insure certain developmentally sound conditions to families without having to remove children from their homes and delegating responsibility for their development to specially trained personnel? His answer is by recognizing the environment in which the mother and child are living, i.e., ecological intervention. The essence of the strategy is a primary focus neither on the child nor parent, nor even the dyad or the family as a system. Rather the aim is to effect changes in the context in which the family lives—enabling the mother, parents and family as a whole to exercise the functions necessary for the child's development. No training program is necessary for either mother or child—simply provide a situation where there is opportunity and status for parenthood and let the participants take it from there.

Bronfenbrenner stresses the need for restructuring the environment which includes the wider community. He states: "the extent to which such a reciprocal system can be developed and maintained depends on the degree to which other encompassing and accompanying social structures provide the place, time, example and reinforcement to the system and its participants (page 48)."

Such a system for support to the child who is developmentally at risk has been conceptualized by Tjossem (1976) who also believes that the best intervention is where communities organize supportive services that enable families to enhance their risk child's development. He fantasizes one such model: pages 24-25.

"Ideally, the approach begins in the newborn nursery. Here, both physicians and nurses are alert

to signs of early risk and show concern for the child's developmental well-being as well as health. In their appraisal, signs of risk in the early mother-infant relationship are not ignored (Brazelton, this volume). With evidence of risk and need for support, mother and child are discharged with an accompanying referral to the community health service for nurse support and observations in the home.

"In her home visit, the nurse first gives expression of the community's interest and support for the future well-being of the risk infant and family. While observant of total family needs as well as the health of both mother and child, the nurse is supportive of the mother's beneficial child care behaviors. She continues her period visits until, after exchanges with the child's physician, determination is made that no risk or continued risk is present. With this determination, she maintains her visits and relationship with the risk child and family and terminates service to the child and family that are doing well.

"In the continuing supportive relationship, the nurse extends her knowledge of child care and training to the child through the mother. For family and child requirements beyond her command, she draws upon her knowledge of community or area resources to bring them into family service. In this manner, referral of the family is made to the community's educational resource upon evidence of the risk child's need for educational assistance in mastering the developmental tasks of childhood.

"The transition from nurse and physician to education services brings with it a comprehensive understanding of the child's health and developmental status and the family's needs and strengths. Upon educational evaluation and acceptance for service, the child and family enter into the home-based training program offered by the educational resource. The individualized training program is implemented by the parents with the guidance and support of the educator. Continuing, as needed, into the preschool years, the educator monitors the family's and child's needs for adjunctive community services and assists in bringing their support to the family." (Tjossem, 1976, pp. 24-25.)

In summary, Tjossem concludes that our knowlege about intervention efforts at this point suggest that certain factors are necessary for success: 1) Supportive services must be initiated early; 2) they must be offered on the basis of perceived risk and need, not diagnosis; 3) they must be family oriented, and support the parent-child interaction system; and 4) they must be sustained (page 25).

Conceivably, these factors may be speculative, but they echo the conclusions drawn from much of the current expertise. More importantly, they essentially represent the approach demonstrated by the Drew Infant/Parent Education Project which is currently proving its effectiveness in this community, and about which we will now hear more.

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Human Service Delivery for High Risk Infants

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Social science research most regularly reports that "problem families," or the "socioeconomically and culturally disadvantaged" families within our society are not only in dire need of all manner of financial, educational, social and health assistance, but most assuredly need to change their ways if they ever expect to join "the rest of us." Most frequently, the research implies that "the rest of us" are where we are because of our "normal/normative" values and behavior, our "true grit" and determination. Seldom is it ever noted that "the rest of us" have certain socioeconomic, cultural, familial and educational assistance, or socioecological support systems that are not available to the "problem" families—street lights, police protection, trash pick-up, friendly and fair grocery store personnel, fresh foods in our markets, health and recreation facilities, and other community services and supports. The "rest of us" assume that these are our due; after all, we pay taxes, vote, clean up, dress up and behave ourselves. Equally, we assume and expect that "any decent mother" who has a handicapped infant will perform all the myriad maternal behaviors required to enable her child to develop to his/her fullest potential. We become upset, morose, depressed, discouraged and indignant when "those" parents do not follow through with "our" therapeutic strategies. After all, the child's needs are apparent, an appointment was made, service personnel were ready and waiting to "intervene," and *they* prohibited us from serving them by not showing, and apparently, *not caring*. Most often, we do not remember: 1) what a hassle one healthy infant is, even with the assistance of child care services, school personnel, family, husbands, etc.; 2) what a greater hassle one healthy infant is when there is a two-, three- or four-year-old sibling around who also needs attention *and* a husband who expects dinner; and 3) what a hassle a handicapped infant is, even with assistance, money, community health services, transportation, etc. available. But how often do any of us imagine a situation in which there is a handicapped infant, a two- and a four-year-old at home, a six-year-old who comes home at noon, seven- and eight-year-olds who arrive home at three, a small house with one bedroom, no family nearby, no car, and income of $800 a month, a moody and/or abusive husband, a neighborhood store where milk costs one-third more than it does in your neighborhood, no street lights, police who when called for help arrive and kill or maim the caller, trash pick-up that is erratic and sloppy, and school teachers who assume that you don't care about your kids 1) because you are the color you are, 2) because you live where you do, and 3) because you don't come to parents meetings?

Now, would you expect the mother in this situation to bring her handicapped infant by bus (remember the two- and four-year-olds) to the hospital for a clinic appointment that you made at your convenience so that you may HELP her and her child? You do—we do—all the time. After all, we have recognized their needs and legislated all this money.

What of the environment? Do you ask about it? Do you provide transportation, child care, someone to be home when the six-year-old arrives from school, day care for the four-year-old? Do we even value these services, or view them as prerequisites for any services that we have designed for the infant and mother? They are not valued by those who award the funds; and *they* don't understand why these folks don't get any better!

The family illustration is not imagined. It characterizes the circumstances and environments that have existed for many of our handiccapped infants and their families—those who we describe as inner-city, poor, minority families. Our definition of inner-city poor and/or minority includes all of the individuals and families within our society who reside within the ghettos across our nation, and who are different from (and therefore disapproved of by) "the rest of us." The inner-city poor and/or minority members of our society are systematically excluded from the benefits of our social institutions, the very sources of support which any society provides for its members, and especially for its families.

Parents cannot, nor should they be expected to provide adequate care for their children in environments which denigrate them, their physical, social and cultural values, beliefs and behaviors, and isolate them from the processes of participation and actualization. Our families are denigrated because they are different, and because we, as a society, do not value differences. Differences make us uncomfortable, so we ignore or deny them—until we can no longer do so, and then we activate the "victim-blaming" process.

William Ryan, in his book *Blaming the Victim* (1972), argued that the underlying philosophy of most human service programs is a victim-blaming philosophy or set of ideas and concepts deriving from a systematically motivated distortion of reality, which is rooted in a class-based interest in maintaining the status quo. Adherents to this philosophy define social problems by ignoring a whole set of ecological factors which ordinarily are considered relevant, for instance, the unequal distribution of income and power, social stratification, and racial group conflicts. As a consequence, "victim-blamers" approach the solution to the problem by looking for defects in individuals or groups of individuals, rather than by searching for defects in the community, environment and/or society.

The key strategy in the victim-blaming process is to define the "problem" population's differences as the sources of their problems. For example, poor people have been examined and found to reside in slum or ghetto areas, have little to eat, poor health and high unemployment rates. Poor mothers reportedly do not provide proper nutrition, stimulation and toys for their babies, and so they do not develop to their fullest. The victim-blamers then argue that the reasons for this inadequate functioning is, indeed, inadequate functioning. Poor people live in the slums because they are poor; they are poor because they do not work; their babies are malnourished because they are not fed properly. The obvious fact that poverty is primarily an absence of money is overlooked or set aside.

Many sincere and committed people are participating in the victim-blaming process--a very subtle process that is cloaked in kindness. However, it is but another version of an old process of viewing victims as genetically inferior; victim-blamers instead attribute the defects to environments such as single-parent families, poverty, absent fathers, cultural deficits, and so on. In doing this, victim-blamers deny the differences that exist in the cultural and social realities of the so-called "problem people." We seem to prefer to pretend that we live in a democratic society. In subscribing to the victim-blaming process, we are unconsciously colluding with the systematic inequities that exist within our society, *and* avoiding the examination of our own complicity in the maintenance of poor and/or minority communities.

The philosophy which undergirds the ecological model for services to poor and minority communities is different, just as our families are different. We believe that human behavior is a function of the interaction that takes place between the person and his/her environment, and within familial, cultural and greater societal contexts. Therefore, if we are to understand human behavior, we believe that we need to know:

1. something about what and/or who the individual is interacting with;
2. how the interactions that occur outside of the individual's immediate setting impact upon the individual; and
3. that the phenomenology of the individual is the critical determinant of "what the environment is like," not necessarily what the environment is, as objectively measured by others. In a multicultural and racist environment, we need to remember that:
   a. culture is a broad conceptualization of not only surface behaviors—food, dress, celebrations—but also includes the deeper sources of the processes by which we each come to know and to think. Different cultural groups have different cognitive as well as parenting styles; and
   b. our society is a racist society, and social realities of the oppressed are different from the social realities of the oppressors.

Most often, poor and/or minority communities are filled with poor and culturally different peoples. They are different because they do not necessarily share the values, beliefs, behaviors, language and perceptions of the "normative" or white middle-class population. A people's culture operates as a pattern for living; it determines their perceptions of themselves, others, children and the roles within the family—the job of a mother, father, siblings—outsiders, social services and their processes, as well as perception of time. For example, black people refer to "C.P. Time," which represents the concept that an event begins when the people get there, not when the clock dictates. Some Hispanic concepts of family roles are not the same as those which are promoted by the dominant cultural group. We need to recognize that *there are many ways to be human*.

In recognizing the diversity and integrity of all human groups and their individual members, we believe that an ecological service model is most responsive to all groups, and most especially to those members of our multicultural society who we've been taught to fear, disrespect and denigrate because of their uniqueness. The implementation of an ecological model seems relatively simple, given the assumption that all people are human. However, because we have been socialized to view differences as deficits, different sets of assumptions and behavioral patterns must be developed if we are to implement such a model. This is very difficult, because attitudes and behavioral patterns are not easily modified. Certain of the differences between an ecological model and the traditional intervention model are:

1. The ecological model assumes that we and other professionals know little, if anything, about these families, their children and their sociocultural realities. They have been excluded from our educational curricula. We further assume that we know even less about a particular family and its handicapped infant.

   Traditional model professionals assume that they know all about these families, why their children are handicapped, and why they've been referred. They believe these families need to be made to look like the rest of us. They also believe that these families all look and act alike, and therefore the individual family is not perceived to be unique.

   Given the ecological model's assumption of the uniqueness of culture and individual families, we must ask and allow the family to inform us as to who they are, what they believe in and value, and what their goals are. We need to know what they feel they need and want from us. We must also allow them to help us to understand the nature and characteristics of their handicapped children—who they are, as individuals, what is helpful or distressful for them, and what they can or cannot do. We also need to know what the parents have done or are doing for their handicapped infants—what has and has not worked for them. We learn and share this information in their homes, as well as in our offices or the hospital, not only to enhance the diagnosis and treatment plan, but to allow the family the power and prerogative to accept or reject us.

   Traditionalists, in assuming that these families must be "fixed" because they are different, do just that, or they attempt to do so, by prescribing and using middle-class normative childrearing techniques, normative foods, toys, stimulation and therapy, without regard to differences in culture. This approach could be described as "melting pot-ology." Its subscribers use home visits as a one-shot deal, to enhance their diagnosis. They evaluate what they see on the basis of their own cultural values; for example: How can you judge if a house is too small for a family, or that there is too much noise?

2. We assume that these families have certain suspicions about us, at best, and negative attitudes toward us at worst, because we represent the society which devalues them and which is not supportive of their cultural beliefs, values, behavioral patterns or language. We represent those so-called emissaries of "good will" who bring irrelevant and irrespective plans and opportunities to them. To alleviate some of this distrust, we define ourselves and our services—what we can and cannot do, what we would like and want to do—and we ask if they are interested in these services. We do not tell them what they must do, what they ought to do, what they need or what they want. Traditionalists, on the other hand, do tell them these things, because they assume that there is only one way to have a family, be a parent, rear a child or respond to a handicapped infant.

3. We assume that any group of families, or any individual family is as deeply caring and capable as any other group or individual family. We also assume that, barring physical or mental disabilities, all families want every possible chance for their children, and try to provide

every opportunity and supportive strategy which they believe is necessary to their infants' development. Therefore, we ask parents what *their* diagnosis and treatment plan is, what *their* goals are, what *they* believe their children need, and how *we* may help them.

Traditionalists have little, if any, confidence in the competence of these parents. They tend to believe that they care very little for their children, and they most readily assume that these parents do no know how to rear so-called "normal" children, let alone handicapped children. Again, they, as experts, determine the diagnosis and treatment plan.

In assuming that all families are capable and caring, we collaborate with them, sharing what we and they know—our experiences and their experiences, our resources and their resources, and most importantly, their goals for their infant—the purpose of which is the ultimate development of relevant and effective treatment plans, strategies and techniques which will enhance the infant's opportunities to grow to his/her fullest potential. Traditionalists assume that these parents have not the slightest notion or understanding of their handicapped infants' needs, or any other relevant knowledge which would assist or enable them to properly care for their children and enhance their chances in life.

4. Finally, when parents appear not caring about or incapable of handling their children, and they are not suffering from any physical or mental disability, we assume that they are not receiving the necessary societal support, or, we assume that their parenting efforts are being blocked by various sociocultural realities (i.e., the lack of money, jobs, transportation, and perhaps the attitudes and behavioral patterns of those who purportedly assist them). Traditionalists usually just assume that these parents don't care, are lazy, ignorant, uncooperative and resistant. They cannot understand why they don't feed their children properly, provide them with adequate stimulation—and especially, they have no understanding of why these people don't keep their appointments.

Because we assume that all parents care and are trying, when they fail to appear or follow through with treatment plans, we ask them what happened. Where's the bus stop? How long does it take? How many children have to come? When do the others get home? Is there a neighbor or friend? How much does milk cost? How much money or time do you have? And so on. We never assume that they don't care, or that they are incapable. We try to determine what gets in their way—the attitude or behavior of the doctor, nurse, welfare worker, social security personnel, ourselves, the diagnosis, the treatment plan, the time of day, and so on. Once they help us to identify the sociocultural and ecological constraints, we try to assist them by collaborating with them in the removal or modification of these constraints, and by being advocates for them and their infants.

We also make certain assumptions about other professionals and service personnel with whom these parents have to relate, for the well-being of their children. These workers have also been socialized to disapprove of these families because they are different, so we ask them for their ideas about the diagnosis and prognosis. We ask them about their perceptions of the handicapped child and his or her needs. We ask about their perceptions of the parents, their knowledge and understanding of, and their responsiveness to their infants. And we ask about their expectations—or lack of expectations—of these parents. We pay attention to their perceptions and attitudes toward the families. Often, they don't believe in either the infants' or the parents' capacities to improve, develop, grow and/or modify their circumstances. Often, they do not respect the families at all. We share with these workers the parents' and our own need for their cooperation, understanding, sensitivity, flexibility and honesty—and our need for their willingness to talk to and not at parents and non-professional members of our team, in language which is respectful and may be understood by all.

Often, professionals argue that the parents will not understand, when in fact, it is *their* inability to express themselves in a manner that is easily understood, their own discomfort in talking with the parents, or their absolute lack of understanding or knowledge of the handicapping conditions of the infants. We, as experts, are not allowed to admit that we are not experts!

We share our knowledge with para-professionals, whose lives are reflective of their knowlege about, experiences with and caring for people. We ask them to help us to help the families.

In summary, we believe that there are many ways to be human, and therefore, if we expect to provide services which are relevant and responsive to

people, we need to develop and have an understanding of people who are different from ourselves. We may not judge them to be hopelessly ignorant, primitive and/or inferior because they do not believe in the same things or behave in the same ways that we do.

If we intend to design and implement programs for these families, we must then surely assess their environments—those in which they reside, as well as all of the other ecosystems within our society that impact upon their daily lives, such as the schools which do not respect their cultural integrity or childrearing behaviors, and all other social institutions whose decisions about who gets the advantages and opportunities impact upon these families. Such assessments give us some beginning information about what may be needed and how it is to be provided. We need to ask: To what extent does or will the environment enhance or inhibit the family's capacities for and efforts in providing supportive environments and behaviors for its handicapped child? What support systems are available to them—both formal and informal systems—and which ones are used, abused, avoided? Why? What are the agency's attitudes and behaviors toward these families? What are the stress factors within the environment—external as well as internal environments? What are the informal and formal networks that enhance or distort and/or destroy family efforts? What are their coping strategies, childrearing patterns, behaviors and goals? (Often their patterns are better and more efficient and realistic than ours.) How isolated is the family? What are its strengths, its weaknesses? Will they be able, and are they able to advocate for themselves and their children?

The emphasis here has been purposely placed upon an external assessment and external strategies and techniques used by families, for, although we have been inundated by data on internal environmental factors, these data have only included information about how these families differ from "the rest of us." As a result of this myopic and monocultural perspective, we continue to locate problems within the people and seldom bring about changes in their realities. Those of us who wish to implement an ecological model for the provision of human services have much to learn. Our social science theories and research have told us little, if anything, about the values, beliefs and behaviors of those members of our society who do not share the dominant culture's standards of value and belief, and even less about how our social institutions function to inhibit their growth and development. What we do know is that they are different. Different does not mean deficient, abnormal, deprived, disadvantaged, unequal or less human. It does mean unusual, rare and unique.

Cultural Pluralism in the Delivery of Services to High Risk Minority Children

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In order to view the value of a pluralistic philosophy relative to programs for infants at risk and handicapped infants, certain basic tenets must be agreed upon:

1. each human being has a right to develop to his or her fullest potential;
2. in order for a highly technical, civilized society to advance, it must be willing to accept its failures along with taking credit for its accomplishments; and
3. a handicapping condition in and of itself is a disabling condition but becomes increasingly so when compounded by being a minority and being poor.

Unfortunately, a significant number of high risk children are high risk because of the interaction of their minority culture and their socioeconomic status. Many of the characteristics of poverty are too often equated with racial and ethnic cultural properties. This erroneous description does not provide us with information regarding the people themselves, but it can give us a lead into why groups of people exhibit certain behaviors and how services to these groups require an alternative approach to delivery.

Poverty is not simply the lack of money for poverty deprives the individual not only of material comfort but also of human dignity and fulfillment. When this state is considered concurrently with individual cultural variations and handicapping conditions, you can begin to see the complexity of the problem. Keyon Chan and Robert Rueda (1979) in their article "Poverty and Culture in Education: Separate but Equal" state;

Surely, poverty is strongly associated with problems in biomedical health and restrictions in socialization factors which are likely to profoundly influence the development of the child. Economic constraints will lead to ill health and restricted opportunities. Just as surely, but separately, cultural conflicts between ethnic minority cultures and assumptions of prerequisites of schooling will result in problems of educability for minority children. Poverty warrants economic, medical, and environmental intervention, while cultural conflicts require a critical re-examination of the assumptions and prerequisites of the hidden curriculum in this pluralistic society. Neither alone will solve the problems of the poor or ethnic minorities in America. However, the confusion of the two may lead to ethnocentric misinterpretation of research and the inappropriate development of interventions.

I will attempt to parcel out cultural characteristics and discuss them from a pluralistic perspective as they relate to service provision, but before I can do that we must come to an understanding of what I mean by a pluralistic perspective. I believe that it was best defined in the Journal of Teacher Education (1973).

To endorse cultural pluralism is to endorse the principle that there is no one model American. To endorse cultural pluralism is to understand and appreciate the differences that exist among the

nation's citizens. It is to see these differences as a positive force in the continuing development of society which professes a wholesome respect for the intrinsic worth of every individual. Cultural pluralism is more than a temporary accommodation to placate racial and ethnic minorities. It is a concept that aims toward a heightened sense of being and of wholeness of the entire society based on the unique strengths of each of its parts. Cultural pluralism rejects both assimilation and separatism as ultimate goals.

While the concept of pluralism may be too much for some to digest after a delicious box lunch, certain elements of the perspective must be addressed if intervention is to have an impact on minority high risk and handicapped children. Looking at several specific examples and how they relate to service provision, let's begin with the family constellation.

Minority families differ from the dominant culture in that they are more apt to exist under conditions of an extended rather than nuclear framework. This extended family usually consists of the immediate family along with grandparents, aunts, uncles, cousins and in the Hispanic culture, "padrinos" or godparents. The extended family may even include close neighbors. As a result the main care given of the child may not be the mother. This role may be filled by grandmother or oldest sibling. Intervention techniques which are developed for use with the mother would not impact on the child if the main caregiver is someone other than the mother. Many of the high risk births are to very young mothers. This situation would naturally require more interaction or assistance from an older or more experienced surrogate.

Another area in which the extended family plays a role is in parent activities which exclude members of the immediate family. A subtle example of this is, if a program provides baby sitting services during the scheduled parent activities, some minorities view this as separating the family unit. They feel that any activities related to their handicapped child also require the attention of the siblings. The extended family has another affect on service provision. The elders in many cultures are held in high regard and are identified as the decision makers in the constellation. Consequently, the success of the intervention efforts may hinge on the decision of these individuals, moreover, if trust is developed between the program and the decision makers, continued involvement will be increased because of the supportive mandates issued by the decision maker.

One more characteristic of the extended family is the role of the advisor. The designated decision maker will identify someone in the family unit whom they feel has demonstrated the best sense, to assist them in the decision making process. While this advisor could be a parent it could also be an aunt or uncle. Observing the dynamics of the family is of much import if any intervention is to succeed. As you know or have gathered, working with the family of a minority high risk or handicapped child is not a cut and dried issue. It is a much more complex social structure than initial observations would have you believe.

Several key points need to be made regarding the area of language. Gustavo Gonzales (1974) in his article "Language, Culture, and Exceptional Children" points out that:

"...many youngsters in the US grow up speaking languages other than English; yet there are those who would impose the same linguistic expectations on them in the early years as they would on native English speakers of the same age. Although we claim to live in a pluralistic society, there are those who would rob others of their native tongue or dialect only to require its learning later as a prerequisite for graduation. Though all languages and dialects have been shown to be appropriate for their time, place, and circumstance, there are those who would relegate speakers of languages and dialects other than 'standard' to an inferior or retarded status." With these thoughts in mind, let's examine the role of language in the provision of services to minority high risk and handicapped children and their families.

While a pluralistic view stresses the use of the native tongue for instruction, many people reject this notion, using the argument that these children must learn the language of the dominant culture. A view with which pluralistic do not disagree. On the other hand, these same individuals also find a second language as an asset. This contradiction is dealt with by a position that English should be taught first. This discounts the language which the family members already possess. Programs which operate from a cultural deficit perspective insist that the language which the child uses be it Spanish, a Black Dialect, Navajo, Chinese, Japanese, etc. is of little or no use in the formal education structure. This would immediately place the child behind his or her peers of the dominant culture, a position which is not often overcome. The relation of language and intellect is well

documented; to discount the language experiences of culturally different children as being unusable in the formal education structure should tell us something about that structure. Especially when we are confronted with figures which indicate a 50% drop out rate among Chicano students. That's a particularly significant figure when you consider that approximately 40% of the public school children in Los Angeles are Hispanic. (Haro, 1979) This recurring situation will certainly require us to look at the curricula approaches which are currently being utilized. Kathryn Clark Gerken (1978) after comparing the performance of Mexican American children on verbal and non-verbal I.Q. tests reported support for previous studies which found that Mexican American children do perform significantly better on non-verbal scales than on verbal scales. She concluded;

"Critics of this study will be quick to point out that non-verbal tests do not correlate well with school achievement and thus, knowledge of higher level functioning on those tests is of little value. However it is this knowledge that must be used to effect changes in our educational programs. If the children are not intellectually deficient, then the reasons for the failure in school experienced by many Mexican American children must be elsewhere."

Getting back to language as it relates to mirority handicapped children and their families. The most obvious area in which this impacts is the ability of the staff to communicate with the child and family. Intervention efforts require fluency in the language of the family. Use of the language is not enough, cultural elements must also be included. Simple translation may not and probably won't be enough. The time required to translate forms which have to be signed by the parents will be time well spent. Regarding medical services, far too much damage has occurred because the parents did not fully understand the directions provided to them concerning the administration of medication or directions regarding what to do for the child. Someone should be present who can translate for the parent. In most cases the parents understand just enough that "a little knowledge is truly dangerous." They pick up only a few words and may be totally out of context. I could go on about the importance of language but instead I'll just ask you to consider these issues when working with minority infants and their families.

The concept of time impacts greatly on service delivery to minority families. This misunderstanding has led to labels such as Colored People's Time or CPT and various other less than complimentary designations. While it would appear that having people keep established appointments would be a minor problem, it often results in much alienation of program staff and other professionals toward the minority families.

Several culturally based reasons exist which result in the apparent disinterest or laziness associated with being late or missing appointments for example; Native Americans consider time as present oriented. Time to them is NOW. Consequently, an appointment next week or a timed activity is not of particular import. Chicanos on the other hand, consider starting time as the time when everybody is present not necessarily 10:00 a.m. or some other designated time.

This aspect of culture is one more point which, while appearing to be trivial, can become a very important consideration.

An article published in *Mental Retardation* (Switzky, Rotatori, Freagon and Miller, 1979) provided me with a definition of curricula "Educational curricula clearly involve questions of value. Educational theories which underly curriculum models reflect the philosophy; social idealism; psychology; optimism; history; politics; and economics of a culture." At this point let's consider the importance of the curriculum. We must examine our own viewpoint and how it is reflected in our personal philosophy, as well as in our basic educational philosophy; because it would be very difficult to separate the two when developing curricula, and even harder when attempting to implement it. Ron Henderson (1980) states:

"...a number of studies have demonstrated that teacher expectations tend to be lower for minority than for majority children. The obvious questions to ask, then, is whether or not variations in exceptions are associated with differential behavior toward students. The answer seems to be yes. While there is little direct information on specific effects of differential teacher behaviors on the school achievement of culturally diverse children, an accumulation of research results does establish the general case that level of student involvement in academic tasks and the nature of teacher-student interactions are consistently related to achievement. These findings are of particular interest when viewed in relationship to research on locus of control and learned helplessness, which provides a theoretical framework to explain how differences in teacher expectancies and interaction patterns may affect

both the socioemotional development and achievement patterns of children with diverse socialization experiences outside the school."

In looking at the issue of basic educational philosophy: is our position the same as what is reflected in the currently available curricula; that is, establishing a standard toward which we can incur change in the child; or, is our philosophy one in which the child's abilities are enriched and strengthened through a pluralistic approach? During the early years of life would it not seem more appropriate to teach the child to interact with his own environment or, better yet, ecology; thus securing a consistency between the intervention program and the home. This subsequently would develop an improved self-image for both the child and the parents, by focusing on the strengths of the culture instead of posing a cultural deficit perspective, and possibly placing them in a situation of diminished self-worth as a result.

How is all of this translated into curricular and instructional considerations? Looking at several minority populations, while comparing and contrasting several cultural aspects, we will arrive at some specific ideas.

Some characteristics which make up a culture would include: language; values; traditions; food; clothing; and music. In focusing on these, does the currently available curricula utilize these elements to maximize the effectiveness of that curricula when it is being implemented with minority children? Few could argue that they do. By transposing these cultural characteristics over those elements cited earlier, which form the basis for curricula, we will begin to see a departure in basic, rudimentary elements. In comparing a minority perspective to that of the dominant culture: the Pueblo's of the southwest possess a high regard for human life, and all living things; consequently, abortions are practically non-existent. On the other hand, the dominant culture has legally sanctioned abortion, and again few could argue that abortion is not extensively practiced. While not condoning or condemning, it is necessary to underscore the significant departure on a very basic issue, and on one element that was previously identified as a cornerstone for curricular development.

Another point for comparison which was mentioned is history; not the subject matter taught, per se, but how differing histories are reflected in the composition of curricula. Until recently, the contributions of minority individuals was pretty much discounted, as they related to the development of our country. While the history of the dominant culture has, for the most part, been clearly documented. Growing up in New Mexico, I often felt an uneasy inconsistency, along with hypocrisy, as I was being taught in school about Jamestown as 'the first settlement in the new world'; at the same time I explored Santa Fe and its buildings, which date back well before 1607.

I've often wondered how someone would explain to Native Americans that we were celebrating a Columbus Day holiday. I was always amused by the question on the Wechsler Intelligence Scale for Children, "Who discovered America"; not because of the question, but because of the response required of the examiner. If the child said, "The Indians," the manual says "No, the Indians were already here. Who discovered America?" How the author knew that the Native Americans were *always* here, I'll never know. If they weren't always here, then they must have discovered America! I also think that it's a tragedy that people learned more about slavery by watching "Roots" than they were ever exposed to in school. I have pointed out these things, not necessarily to highlight the discrepancies, but to stress that, if the history of a culture is reflected in the formulation of curricula, the historical perspectives of minorities has had little, if any, impact.

Examining the element of economics: all anybody has to do, is compare the mean income of minorities to that of the dominant culture, to see that there is a significant descrepancy here as well. Continuing with these comparisons would result in the same observations. If, in fact, educational theories which underly curriculum models reflect the philosophy, social idealism; psychology; optimism; history; politics and economics of a culture, we certainly have a long way to go before curricula are developed which do justice to the minorities of this country.

Another language variable, which will affect curricula and instruction, not mentioned before, is that some Native Americans do not have a written language. Consequently, if instruction is to take place in the native tongue, the person conducting the activity must display a high level of fluency in the language.

Music is another specific aspect of culture which can be readily substituted into the curricula. "Mary had a Little Lamb," and "Old McDonald had a Farm" are examples of typical pre-school songs which, while not eliminating them, could be utilized as supplemental material to culturally relevant

songs. Food is very adaptable element of culture. Activities centered around food are easily implemented. Traditions would certainly affect programmatic, as well as curricular, aspects. For example: Chicanos are very open in their expression of feelings toward each other consequently, they tend to touch, hug and overtly express other emotions. This could certainly be integrated into our programmatic activities, what better way to demonstrate acceptance to infants and young children.

Donald Stedman (1977) in his review of research on early intervention programs, synthesizes the findings and makes several key points which relate directly to intervention programs for minority handicapped children, and subsequently curricula. He writes, "The manner in which a child is reared, and the environment into which she/he is born, have a major impact on what she/he becomes." He goes on to list the following findings:

1. Factors, such as race and sex, do not appear to be related to the child's ability to profit from intervention programs.
2. The family's methods of establishing social roles leave little doubt that early family environment (parent language styles; attitude toward achievement; parental involvement and concern for the child) has a significant impact on the child's development before she/he reaches his or her second birthday.
3. The effects of a stimulating, or depriving, environment appear to be most powerful in the early years of childhood when the most rapid growth and development take place. Therefore, home-based intervention programs, or one-to-one teacher/child ratio stimulation activities, appear to be the most appropriate and effective during this period.
4. There is evidence that early intervention programs for children are strengthened by the involvement of the child's parents.
5. Where access to children can be gained in the early years, preferably during the language emergent years (one to two years of age), intervention programs will be more effective than those begun at later ages.
6. A systematic, organized program can contribute significantly to a child's social and intellectual development between the ages of four and six years.
7. The quality and motivation of the staff are directly related to the success of the program and, therefore, are prime factors in determining the extent to which a program is exportable or replicable.

Given these findings, the implications for curricular modifications become more obvious; particularly in light of findings associated with "parental language styles." Certainly, use of a different primary language in the home would have considerable effect on this variable. Other findings which address variables, such as the "language emergent years, the home as the focus of the child and the importance of parental involvement," would support the notion of adapting, or developing, curricula which would provide consistency between the intervention programs and home environment. It might be well to note at this time that the majority of minority parents who participate in the programs, and are indirectly affected by the curriculum, have more than likely had a frustrating experience with organized educational systems. Consequently, they will be less apt to become actively involved in a program which appears to them to be a downward extension of the school curriculum: a curriculum which was not responsive to them and their individual needs as children.

Stedman makes two very important points in his discussion of the problems with intervention efforts. They are: "There is a typical failure to individualize programs. That is, there is a homogeneity of treatment, whether it be social class; I.Q. level; sex; minority group; or other critical features across heterogeneous groups." And, "There are often significant cultural differences among minority and ethnic groups, leading to differential reactions to intervention programs. This may lead to exaggerrated responses from the children in either direction. Also, there are, in many cases, extreme value differences between subjects and their families and the project staff which may lead to inadequate, or inappropriate intervention components and results." These statements require no further elaboration.

In summation: Curricula and Instruction should be developed and implemented in a way which capitalizes on the strengths of the minority culture, and does not reflect a cultural deficit perspective. This must be reflected in the educational program philosophy. It is no longer enough to employ minorities and culturally sensitive individuals to implement the programs, and rely on them to modify the curriculum to meet the needs of the targeted handicapped minority population. This practice has occurred too often, and we are left with the same basic curricula with no information and no documentation regarding these

modifications. It is time that consistent modifications to existing curricula be reflected in the development of curricula which focus specifically on, and result in, the generation of culturally sensitive curricula for those populations.

Cultural mores must be considered when implementing curricula: especially if parents are to be involved in the process. Ignoring these aspects will, undoubtedly, lead to less parental involvement and, subsequently, less effective intervention.

Parent programs should focus on the systematic and consistent parenting skills. Concentrating on, and supporting, the strengths of the parent, rather than dwelling on perceived deficits.

While minority handicapped children and their parents require a modification or re-vamping of current practices, this modification should not be misconstrued as a plan to remediate presumed culturally centered weaknesses, but rather an approach which highlights strengths. In other words, putting special education philosophy into practice.

Some of my ideas may sound somewhat far-fetched but I would like to cite one final reference and paraphrase a statement made by Rev. Jesse Jackson. Hazard and Stent (1973) remarked after stating that according to the 1968 census over 50% of the school aged population were of different cultural and ethnic background "...to postulate our education on bases other than cultural diversity and pluralistic notions seems to ignore the realities of our schools' population."

And finally in recent presidential elections the largest plurality attained was just over 500,000 votes. With seven million black voters in this country, the hands that once picked cotton are now picking presidents. This could also be said about the Hispanic population with one difference, their hands were picking lettuce and grapes!

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Developmental Activities for Infants Using the Family Environment

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Learning must go on all of the child's day. It cannot be left entirely to any school center. Caretakers must be active and aware participants in any stimulation program that expects to achieve maximum results. For poor and underprivileged families, parent participation is difficult. Lack of transportation, isolation, poor nutrition, inadequate living space, poor medical care, lack of child care and ineffective communication are a few of the challenges that must be confronted in an ecological model designed to serve these families. Many of these challenges must be met before as well as during the implementation of the Individualized Educational Program. I am going to discuss with you some specific procedures for meeting these challenges and delivering services to the infant. These field-tested procedures evolved throughout a three year service delivery period.

Intake Procedures

Intake procedures for an ecological model include four important components. They are the screening interview of the family, the environmental checklists, the medical summary and the feeding evaluation. The medical summary will usually show the diagnosis and note any contraindications. For this model, the worker must learn what the diagnosis means—not simply in general—for that particular infant; because what is extremely important is that the worker be aware of the family's understanding of the diagnosis and what the family's expectations of the infant are as a result of this understanding. The family's understanding would include the cause—if known. If the cause is not known, that should also be understood. Parents always want to know why or how the condition came about. A frequent question from mothers is "Was it something that I did?"

These issues must not be left undiscussed. What can be done is another area for clear understanding. The worker must know what the parents have been told about medical treatment for the baby's particular condition, when and how treatment is to take place and what is the expected outcome of that treatment. The worker will also need the name of the physician explaining the diagnosis to the parents. In some clinics, different physicians may see the child on each visit. It is also important to know to whom the diagnosis was explained. This is especially critical in the case of teenage mothers. Many times doctors will talk only to the mother and overlook her lack of experience and possible difficulty in understanding what is being explained to her. When this is the case, the physician *must* be advised to include the grandmother or whoever supports the mother. When necessary, the support person is helped by the worker to communicate this request to the physician. When the medical diagnosis is not clearly understood by the family, or when there are questions about the medical diagnosis and treatment, a family review panel should be arranged. A family review panel would include parents and infant meeting in a relaxed and friendly atmosphere with project physicians and family worker to discuss the infant's medical condition. In order to provide the most effective

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treatment plan, this service must be included in an ecological model. It is needed to provide family and persons serving the infant with correct, clear and ongoing communication about the infant's condition. It gives parents and staff the information and support needed to make decisions about getting additional medical services and involving other agencies. It enables the parents to improve communication with other physicians and agencies providing services to the child. Some families may not need this service at the outset. Most families will need the service before the treatment period ends. All persons working with the infants will need this service throughout the service period. Physicians who are interested in community medicine and who have the ability to simplify medical jargon do well in working as team members to provide this service. The Drew Infant-Parent Project utilizes the services of two such physicians.

A feeding evaluation will show frequency of feeding, problems with oral functions (a formal checklist of oral abilities should be included), and problems with elimination. Now, we may be great experts on helping an infant improve his sucking mechanisms while overlooking the most stressful feeding problem of all — no food. Many infants in poor communities have few opportunities to eat. It is not uncommon to find infants who have never had formula that was not diluted. Lack of food is an emergency. That this type of an emergency will occur must be anticipated and planned for. Therefore, a source for emergency food supply and a source for continuing food supplement must be identified. The source of continuing food supplement used by the Drew Project is the Women's Infant's and Children Supplemental food program also known as the WIC program. Other sources in the community should be identified for emergency food assistance. Donations of non-perishable items may be accepted and kept on the project site. A specialist on infant feeding problems should be available for consultations.

Some of the important things we found we needed to learn from a screening interview included: how the parents heard about the project; what problems the parents see the child as having; the parents' understanding of the project and what services the parents have heard that the project provides and who explained this to the parents; the family's response to the infant (cultural and social values, interrelationships, behaviors); the family's strengths i.e. relatives, friends, community churches (we have used the church effectively in locating housing); family or child involvement with other agencies; if accepted into the program, what specifically does the family seem most interested in (home visits, infant developmental stimulation, care of newborn, parent groups, other interests); what additional referrals will be necessary.

A listing of support community resource agencies and a contact person in those agencies is a must. Project inservice training that includes inviting resource agencies to participate is an excellent way to establish support relationships with community agencies.

The environmental checklist provides a picture of the home-family environment. The general areas are housing (type, number of rooms, number of people, furniture, telephone, heat); transportation (car, busline near, knowledge of use of public transportation); nutrition (need for food stamps, WIC, garden); general family health (illness, accidents, disease); family finances (Is there any income?); family changes (new family members other than infant, loss of family members, return of family members); family knowledge of community environment and its resources (police, paramedics, medical care facilities, educational facilities, child care); recreation (toys, playground near, park); income changes; job changes; job loss; eligibility for support agencies. An environmental checklist frequently indicates that other family needs must be met before beginning to work directly with the infant. The Drew Project found families without food, five family members in one room without heat, families without sufficient clothing, families where children were neglected or abused, families with other children who were seriously ill.

Additional support services needed are agencies that will donate clothing and a team of professionals who work with abused and neglected children. The Drew Project is fortunate to have the Charles R. Drew Med-Scan (Suspected Child Abuse and Neglect) team. This Med-Scan team works with the specially trained child abuse unit of the Los Angeles Police Department. A Scan team is a multi-disciplinary group organized to cope with the problems inherent in the identification and reporting of child abuse and neglect. Such a team also includes specialists in intervention and treatment who are familiar with and sensitive to the family environment and who can work with families to make the home a safe place for the child whenever possible. The Med-Scan team aids the police department in modifying police service procedures and informs the judicial system of the effects of judicial decisions on the well being of poor and/or minority children.

Assessment

Finally, we are ready to begin working with the infant. How is the infant assessed in an ecological model? For screening and developmental profiles, the Denver Developmental screening test and Developmental Programming for Infants and Young Children, also known as the Michigan, are used in the Drew Program. No test for screening or measurement of development is absolutely suitable in all instances. For the population served in this model, the profiles are used as guides and for providing an opportunity to learn about the infant and caregiver's interaction. Once the tests have been administered in the standardized manner for validity, augment the results with the following important information: Find out what the mother enjoys about the infant, what the infant's responses to the mother are (e.g. What makes the infant smile?), what opportunities the infant has for developing the skills necessary for doing the test items that involve toys, food and interacting with other people. These are major areas of self satisfaction in which an infant learns very early that what he does makes a difference *for him*. Infants in poor families are most lacking in opportunities to express themselves positively in these three areas. The infant who is handicapped and poor—then—will receive frustration as a result of his environment as well as his handicap. Therefore, the screening and testing must not only be used as indicators of the infant's development. They must also be used as guides for planning ways to involve the infant in play and for stimulating his interest in acting on his environment, for working to meet his own needs for food and for engaging the attention of others in positive ways. For example, when environmental conditions indicate, we are concerned that the infant is able to bring his hands to midline so that he can hold his own bottle and feed himself. A mother who is under stress of caring for several other small children will respond positively to her infant's ability to perform this task. In an ecological model, we act on that reality. We want to know if he has toys of his own, what kind of toys they are and how he plays with them. We care about how *frequently* he smiles and what situations evoke his smiling, who the infant spends his time with and how and where that time is spent. The physical evaluation of one infant revealed increased muscle tone and loss of range of motion. When she was referred at nine months she was unable to roll over. An indepth environmental assessment revealed that the mother held the baby on her lap and watched television from 11:00 a.m. to 4:30 p.m. daily. Now clearly, there are implications here for concerns beyond muscle tone and loss of range of motion when writing the Individualized Educational Program. In a ecological model, we must examine the infant's conditon within the context of his daily environment.

We found that assessment needed to include:

1. *Objective findings* taken from the medical summary, developmental screening and testing instruments, specialists consulted, and other formal evaluations.
2. *Subjective findings* from the screening interview, the checklists and additional involvement with the family.

For this model, anecdotal notes provide an efficient picture of infant-family dynamics if the family's views are included in the writing of those notes. These notes are important for assessment and for the entire service period.

Individualized Educational Program

In an ecological model, it is usually necessary to write an IEP for the infant and the infant's family. The IEP for the family includes goals which will affect the infant's well being. The family IEP is written with the family's participation and it states plans for the goals desired by the family. Such goals may include finding housing, returning to school, learning to use public transportation, learning to communicate effectively with agencies, etc.

The IEP for the infant consists of three major parts:

1. Specific goals—e.g. The infant will be able to feed himself finger foods.
2. Behavioral objectives—e.g. The infant will grasp the object 3 of 3 times when presented and hold for 5 seconds. (The object may be a "juicesicle" to be held and eaten.)
3. Activities—e.g. grasping, squeezing with support, holding a variety of toys and objects.

The criterion for a behavioral objective is presented gradually and specifically so as not to overwhelm the parents and so that the parents learn to appreciate small gains as we work toward larger goals. The criterion level is gradually increased. Activities are presented as the family is able to work them in. Activities are demonstrated and written by the Infant Worker each week. Activities are listed in a few words. In areas that show no delays, age appropriate activities are suggested. Parents are encouraged to make up their own activities. (The infant's older siblings are often very good at making up fun activities and teaching them to other family members.)

The following are five important points to remember when writing the Individualized Educational Program:

1. The infant must remain out of bed during the day. With the exception of special cases, he is placed in bed only for nap and bedtime.
2. Stimulation activities should not interfere with an infant's ability to explore and develop unique methods to compensate for his handicap. Before deciding how to help an infant compensate, observe and learn from his own efforts to approach a task.
3. Modeling by the Infant Worker is crucial. The affection, acceptance, handling and cheerful interacting with the infant by the worker validates the handicapped infant as a good human being and gives permission to the parents to accept the infant.
4. In an ecological model the extended family is the most important source of support in the implementation of the IEP. The extended family in this model includes parents, siblings, grandparents and other relatives and friends. The Infant Worker becomes a part of the extended family and acts as a family resource. When the infant and caregiver are isolated and without relatives, the Infant Project becomes their family.
5. Support agencies are very important to the implementation of the IEP.

The parents of the infants served by the Drew Infant-Parent Education Project care about their children. But, because they are isolated from society, they have little opportunity to express that caring in ways that will allow them and their children to grow. In numerous situations, what they know of the society at large is learned through what they see on television and are able to assimilate into their own limited and often harsh experiences. Their expressions of gratitude at finding new ways to use the strengths they already have would cause most people to weep.

Our findings suggest that the nuclear family is not a sufficient model for the concept of family in all communities, and that we must respect the extended family by maintaining its integrity and utilizing its members whenever necessary for the growth and development of minority children. Whether or not the nuclear family is more ideal does not mean a damned thing for the survival of infants whose needs go unmet in such a setting. In an ecological model for the Intervention with Innercity Poor and/or Minority Handicapped Infants and their families, the realities leave little room for idealism. The major task is helping the families learn to use their environment in a way that will help the infant survive that environment.

An Ecological Model for Intervention with Inner-City Poor and/or Minority Handicapped Infants and Their Families: The Community

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We are pleased to be here today to share with you some of our experiences and ideas for service to high risk and handicapped minority and poor infants. The issues today are increasingly critical. In Los Angeles County the Board of Supervisors are attempting to deny services to undocumented immigrants. This, of course, will mean less or no services to pregnant women and less deliveries in properly equipped hospitals for this population. Already Los Angeles County has instituted charges up to $56 per visit for pre-natal and well baby care. The results of this policy are obvious. So, while all research and experience indicates that proper pre-natal and well baby care prevents handicaps and developmental problems, and some parts of health services are committed to carrying out such policies, other branches of government are destroying years of established services. It is against this background of reality that we are discussing the issues of appropriate services for inner city high risk infants.

In the past decade, with the development of highly sophisticated infant intensive care units, the neonatal mortality rate has diminished as a result of increased survival of low birth weight and other high-risk infants. During this same period it has also been recognized that these high-risk infants have the greatest chance for subsequent developmental abnormalities. Therefore, a great deal of effort has been focused on early identification. It has become increasingly clear, however, that despite the development of special care nurseries and specialized although limited identification/intervention programs, the overall incidence of subsequent developmental problems and significant illnesses in the first year of life are extraordinarily high. This is especially true in low income minority populations.

Studies of handicapped infants and children have emphasized that socio-economic status, ethnic or subculture group membership, occupational activity, marital status and other related factors are critical in determining the numbers of handicapped children and outcomes for them. Even with limited experience it is clear that only by providing appropriate early intervention that takes into account and accepts the culturally different parenting styles and assists parents in overcoming environmental restraints will the outcomes for a large segment of poor minority handicapped children be modified and improved. Recent mortality and morbidity statistics for a random U.S. population by the Robert Johnson Foundation Study indicated that 29 percent of high-risk infant population suffered from congenital abnormalities, developmental delay or significant illness by one year of age. These figures increase in relation to factors that often characterize low income, minority populations. Infants of non-white women, very young women, and women with limited education were found to be at highest risk for post-neonatal morbidity and mortality. Wegman in an article in Pediatrics in 1978 noted that there is a significant increase in morbidity and mortality rates for minority populations which occurs post-neonatally; that is between two to four months after they have been discharged from hospital care. This finding suggests that a very real risk for minority infants exists in events that occur after the initial period of hospital care and discharge. Therefore, in order to reduce the long-term morbidity and mortality in high risk, minority infant populations, it is important for us to examine factors and events affecting the high risk infant's state of health beyond the neonatal period, as well as during the initial hospitalization. R. Hoekelman in his article entitled "What Constitutes Well Baby Care" published in Pediatrics, 1975, indicated that in addition to the need for normal well baby care and parent guidance, "those infants requiring medical care in neonatal special care nurseries present a host of potentially handicapped, developmental, psychological, audiological, ophthalmological, and neurological problems." He goes on to say, "Furthermore, these infants often require specialized care when they return home which may severely affect parent-infant interaction and the family's subsequent psychological adjustment." The high-risk infant, therefore, requires not only early

identification, but an ongoing and effective follow-up program that can identify and treat medical, developmental, and psychological problems as they arise, as well as offer preventive medical care and therapeutic services for the child and appropriate education for the family.

Multiple governmental programs have attempted to address and remediate these child health problems by developing a large number of follow-up and health care programs for high risk infants. Unfortunately, most of these programs failed to provide *comprehensive* child health care and, instead, focused only on individual issues. As a consequence, a fragmented health care system developed that provides individual services (for example, developmental assessment, screening for hearing, parent counseling, ophthalmology exam, etc.), in differing locations and with differing admission requirements and time schedules. The resulting patchwork of programs not only fails to provide total comprehensive care, but have also proven inaccessible to many parents. This is particularly true for low income minority groups who are often restricted by inflexible work schedules, transportation difficulties and the lack of sophistication to manipulate the system. Currently, when most high-risk infants in a minority community are discharged from the nursery, there is no easily definable entity which can be looked to for coordination, support, and counseling. What limited services exist for poor minority children generally do not include parent training as the key to influencing outcomes for the infants and young children. Medical, educational, and social service agencies are generally unresponsive to the cultural differences and linguistic needs of the populations they are established to serve. Against this background, we will discuss our region and some of our experiences.

The Los Angeles County Southeast Health Service Region, served by the Martin Luther King, Jr. Hospital and the Charles R. Drew Postgraduate Medical School, is located in a uniquely disadvantaged area. The population served by the King/Drew Medical Center is 40 percent Black and 19 percent Hispanic. It is believed that this latter figure may be grossly underestimated because of the existing socio-political climate. The economic level is one of the lowest in the County: 22 percent of the total population receives public assistance or welfare. In the area immediately surrounding the hospital, Watts, 45 percent of the families receive public assistance.

The region continues to have the highest live birth rate in Los Angeles County (22 per 1,000 population). This is due primarily to the high birth rate of the Spanish surname population which is 53.4 per 1,000. The region also has the highest infant mortality (17.4 per 1,000 births) and the highest neonatal mortality (12 per 1,000) in Los Angeles County. Of great concern is the large number of births to teenage mothers. This region has the highest birth rate in the age group ten to fourteen years of age; one quarter of all births are in the age group 15 to 19. These infants are doubly at risk. The Robert Wood Johnson Foundation study on 1,000 12-month-old infants in eight high-risk communities showed the following:

1. 10.7 percent of all babies born to mothers under 18 years of age had developmental delay or congenital anomalies, as compared to eight percent in the population as a whole.
2. Teenage mothers (under 16 years of age) are at high risk for low birth weight babies, 17.2 percent of all babies born to mothers under 18 years of age who were low birth weight (under 1,500 grams) had developmental delay and/or congenital anomalies.

The community is medically underserved, social services are difficult to obtain, and parents are frequently not aware of the special financial and other resources for handicapped infants. Some of the very young mothers do not have skills necessary for nurturing and caring for an infant. In addition, of course, a handicapped infant requires many specialized skills.

To begin to meet even a portion of the critical needs of the high-risk infants in our community a program was established four years ago with Bureau for the Education of the Handicapped funds and has continued with Regional Center funding. We serve a portion of the handicapped infants primarily from our own Special Care Nursery. Our program was and continues to be home based and family oriented. Our experience has verified that if intervention is to have any success, parent training is the key and family involvement within the cultural context and the child rearing style of each family is required. New research of home based programs for infants reported in the December, 1980 Child Development Journal by Gray and Wandersman substantiate much of our experience. They indicate that middle class parents have made the greatest use of intervention programs. Comparison of our program with others indicated that this was initially ture for us as well. When we were able to modify our expectations and to fit our program into the real life of the families we served, families became increasingly involved. These issues

included time, space, and a renewed understanding on our part of the role of grandmothers.

Critical for our staff working with families was the constant review of our own values and how these compared to the families we were serving. Intervention pre-supposes making changes. It is critical that the proposed changes that the staff is working toward are the same as the goals and aspiration of the families being served. Otherwise, staff quickly outlives its welcome.

Another critical area is how staff utilizes its relationships to enhance the family's ability to function independently and to become the main advocate for the child's needs. It is far too easy to foster dependency and leave the family and child worse off than if we had never been there. The staff has to encourage the parent's own problem solving techniques and encourage the utilization of their own resources and extended family, where available.

Sometimes by placing new demands on an already over burdened family staff can increase a parent's sense of helplessness and hopelessness. Sensitivity to how much a family can undertake becomes vital.

The awareness that differences, whether they are cultural or class simply represent differences and not deficits must become a constant in working with families. This is perhaps the hardest task of all.

Critical in providing services, therefore, is the staff. Over a period of four years we have found that the best workers with families are community residents with similar cultural and linguistic backgrounds. Ongoing training and intensive appropriate supervision is vital. However, we have found that it is far easier to train a community worker to do an appropriate developmental assessment of an infant than to train a Ph.D. psychologist to appreciate and understand rural Mexican child rearing practices.

We also believe that programs should be small. Even though it may make for more administrative problems small programs can remain more responsive to the people they serve and have a greater ability to remain flexible.

Programs also need to be unique. Each community is different, each population served is different. There is no way to design a program that will serve poor-middle class and rich children, all ethnic groups, and rural, urban, and suburban families in a similar, let alone, identical way. Every program must be designed to meet the very particular needs of the families it will serve. These include many variables such as culture, survival skills, aspirations for their child, attitudes toward handicapping conditions, child rearing, family roles, etc. Since the greatest differences in all of these factors exist between institutions and the poor and culturally different programs that are not developed to meet the specific needs of a locality will be least successful where they are most needed —in inner city poor minority communities.

Even as we developed a successful model we were unable to serve all of the children who were referred to us. And these are the children at greatest risk. We were not and still have not been able to develop a successful way to reach to families who are the most disorganized and where alcohol and drugs are used. These families are reluctant to trust any outsider and because of their disorganization have great difficulty in following any prescribed program for their infant—this includes feeding and sleeping as well as meeting the child's medical and developmental needs. Although this group represents a very small portion of the infants born in the region, some approaches must be developed in order to reach these babies. More discussion must be initiated between infant programs, neo-natal intensive care units and drug and alcohol rehabilitation programs. This is an area that no one is doing anything about and no one even talks about.

I want to close my presentation to you this morning with a heartfelt plea.

In the next months and maybe even years, those of us committed to services for children are going to be hard pressed. It will be hard to keep our cool and to remember everything we learned. It will become easier in the fight to save any services for children to forget what we have learned and be ready to settle for anything however poor the quality.

If we only leave you with one thought—services to high risk, poor, and handicapped minority children that do not take into account the aspects of differences will be unsuccessful and cost ineffective. Society will pay over and over again to care for these children in Special Education, by institutionalization, in jails, and by chronic unemployment and violence. Society will pay over and over again for these children because by implementing an inhumane policy, we all become part of the inhumanity. It is not good enough to have something. We must have something that works and what works are quality programs for intervention that take into account the uniqueness of every population to be served.